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ABSTRACT

This paper highlights the public and private health insurance options for young people with disabilities or chronic health conditions including several recent Federal initiatives to increase access to health care for working adults with disabilities. Discussion of public health insurance eligibility and coverage focuses on aspects of Medicaid and Medicare including eligibility for children and adults with disabilities, medically needy children and adults, eligibility through Social Security Disability Insurance (SSDI), SSDI work incentives, and the State Children's Health Insurance Program. The section on private health insurance explains the Health Insurance Portability and Accountability Act of 1996, the Consolidated Omnibus Budget Reconciliation Act, eligibility for extended coverage through a family health insurance plan, and eligibility for individual coverage. The final section addresses health care implications of federal initiatives for young people with disabilities. These include the Ticket to Work and Work Incentives Improvement Act of 1999, extending Medicare coverage for SSDI recipients, the Presidential Task Force on Employment of Adults with Disabilities, the State Partnership Initiative, the Healthy and Ready to Work initiative, Department of Education systems-change projects, and efforts of specific agencies. Appended is a list of acronyms. (DB)

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Youth with Disabilities in Transition: Health Insurance Options and Obstacles

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Youth with Disabilities in Transition: Health Insurance Options and Obstacles

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Introduction

Obtaining or maintaining health insurance coverage, either private or public, is a major issue facing young people with disabilities and chronic conditions as they leave high school. As their life circumstances change—going to college, getting a job, living independently—these young people must understand how to ensure continued access to health insurance. While some will continue to receive Medicaid or extended coverage through their family's health plans, others will have to obtain public or private insurance for themselves.

Data from the U.S. Census Bureau indicate that people with disabilities are more likely to have public health insurance and less likely to have private coverage than people who do not have disabilities. Almost 80 percent of individuals ages 22-44 who do not have disabilities have private coverage, 3 percent have public insurance, and 17 percent are uninsured. In contrast, in the same age group of individuals with disabilities, almost 58 percent have private coverage, 22 percent have public insurance, and almost 20 percent are uninsured.

Draft Report, *Summary of Data on Young People with Disabilities in the United States*, National Institute on Disability and Rehabilitation Research and Social Security Administration (July 1999).

As young people with special health care needs enter the competitive labor market, access to health coverage is a critical issue. The majority of working adults receive private health insurance through their employers. However, many young people with disabilities do not have private coverage because they have part-time jobs with employers who do not offer health insurance benefits or their wages are so low that they cannot afford to pay individual or group health premiums. The potential loss of public health insurance coverage through Medicaid and the high costs and limited benefits packages of private insurance are often cited as key obstacles to employment for adults with disabilities. These factors are also major obstacles for young people with disabilities who are seeking their first full-time job.

For *Re-charting the Course: First Report of the Presidential Task Force on Employment of Adults with Disabilities* (1998) visit

<www.dol.gov/dol/_sec/public/programs/ptfead/rechart.htm>

The rules and regulations for public and private health insurance are complex and vary widely among States. This paper highlights some of the public and private health insurance options that young people with disabilities or chronic health conditions and their families can explore, describes several recent Federal initiatives that may increase access to health care for working adults with disabilities, and lists additional informational resources.

Public Health Insurance: Establishing or Maintaining Coverage

Eligibility rules for public health insurance programs are complicated and can be confusing for youth, families, and professionals. Although there are many ways that youth with disabilities may qualify for Medicaid or Medicare, the following discussion focuses on the most likely scenarios as this population leaves school or begins work. A list of key questions to ask when exploring public health insurance coverage options appears at the end of this section.

Medicaid

Overview

For *Medicaid Eligibility for Individuals with Disabilities*, by Andy Schneider, Victoria Strohmeyer and Risa Elberger, Kaiser Commission on Medicaid and the Uninsured (July 1999) visit

<www.kff.org/content/1999/2150/>

The Medicaid program (Title XIX of the Social Security Act [SSA]) provides medical assistance for selected groups of low-income individuals and families. Funded by both the Federal and State governments, Medicaid is the country's largest source of health care financing for low-income adults and children with disabilities.

The Urban Institute estimates that approximately 21.3 million children (age 0-21) are covered by Medicaid. In addition to the current enrollment, the Agency for Health Care Policy Research estimates that an additional 4.7 million uninsured children are eligible for Medicaid, but not enrolled.

For *Medicaid Eligibility for Families and Children*, by Andy Schneider, Kaiser Commission on Medicaid and the Uninsured (September 1998) visit

<www.kff.org/content/archive/2106>

Among the total population of children receiving Medicaid or who are eligible for it, it is estimated that about 20 percent may have disabilities or chronic conditions.

States have considerable flexibility, within broad Federal guidelines, to structure their Medicaid programs. As each State determines who is eligible, the types, amounts, and duration of services covered, and the service reimbursement rates, the Medicaid Program varies considerably from State to State as well as within each State over time.

Under Federal law, some Medicaid eligibility categories are "mandatory", i.e. States must cover children and adults in these categories if they choose to participate in the Medicaid program. Other categories are "optional;", i.e., States can elect to provide eligibility to individuals who meet the necessary criteria. One significant optional category for children and adults who meet certain disability standards and have high medical bills is the "medically needy" category. Some Medicaid categories apply to all lower income children, but others affect only children with disabilities.

All Medicaid-eligible youth under age 21 are served by the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program. By Federal law, EPSDT provides comprehensive benefits including preventive, primary, developmental, and long-term care services

to eligible children. Health care services identified under the EPSDT program as "medically necessary" for eligible children must be provided by Medicaid, even if those services are not included as covered services in the State's Medicaid plan. The importance of Medicaid for children with disabilities and chronic health conditions cannot be overstated. The program covers the full range of health care services that these children may require, including assistive communication devices, durable medical goods, nutritional supplements, personal assistance, and speech, physical, or occupational therapy.

For *HCFA's Medicaid State Manual: Early and Periodic Screening, Diagnosis, and Treatment of Individuals Under the Age 21* – Section 5000 visit

<www.hcfa.gov/pubforms/pub45pdf/smm5t.pdf>

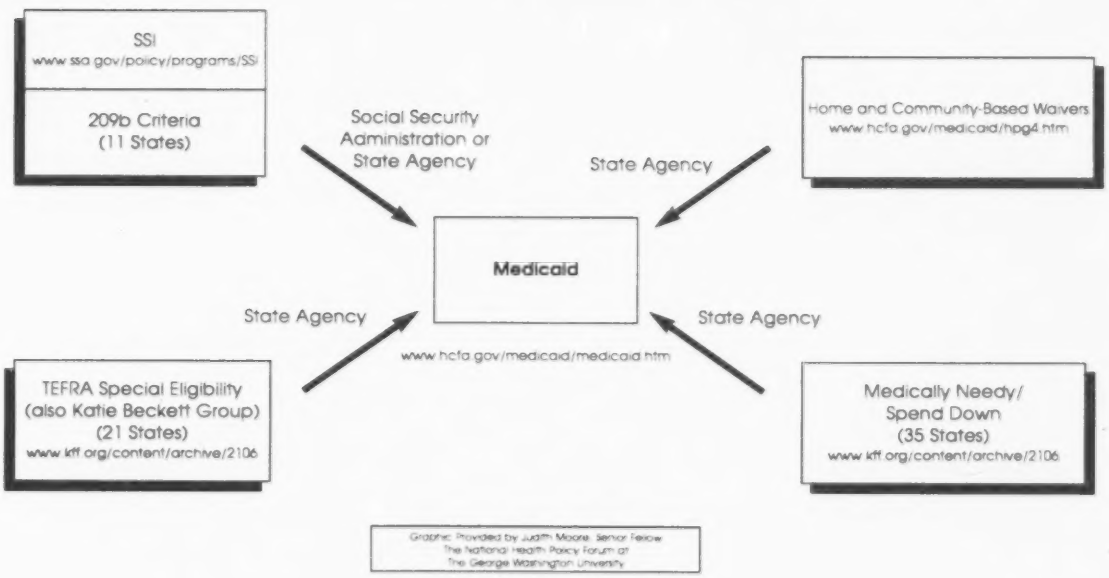
A common misunderstanding is that working families cannot qualify for Medicaid. However, the U.S. General Accounting Office found that uninsured children who qualify for Medicaid are most likely to have parents who are self-employed or employed in small businesses and whose income is too low to afford private health insurance. Lower-income working families should check with their State Medicaid agencies for information about the income guidelines.

For *Medicaid: Demographics of Nonenrolled Children Suggest State Outreach Efforts*, U.S. General Accounting Office (March 1998) HEHS 98-93 visit

<www.gao.gov>

The chart below highlights different paths to Medicaid for disabled children. The following discussion highlights issues for young people with disabilities to consider as they may qualify for Medicaid even when they begin to work.

Paths to Medicaid for Disabled Children



Note: See <www.kff.org> or call 1-800-656-4533 for Kaiser Commission on Medicaid and the Uninsured reports with easy-to-understand explanations of Medicaid's complex eligibility rules, including: *Medicaid Eligibility for Individuals with Disabilities* by Andy Schneider, Victoria Strohmeyer and Risa Ellberger (July 1999) and *Medicaid Eligibility for Families and Children* by Andy Schneider (September 1998).

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Eligibility for Children with Disabilities and Chronic Health Conditions

For December 1999 children's SSI program statistics visit

<www.ssa.gov/policy/programs/SSI>

Supplemental Security Income (SSI) Program. The Supplemental Security Income program (Title XVI of the SSA) provides monthly cash benefits to individuals with disabilities. To qualify, adults and children must meet both financial and disability criteria. The program is funded by Congressional appropriations.

In most States, SSI-eligible individuals automatically qualify for Medicaid. However, eleven States (commonly called the "209{b}" States after the relevant section of the SSA) do not provide Medicaid through the SSI program because they use more restrictive disability definitions. In these States (In 1999, Connecticut, Hawaii, Illinois, Indiana, Minnesota, Missouri, New Hampshire, North Dakota, Ohio, Oklahoma and Virginia) individuals with disabilities must make a separate application for Medicaid. Also, eight states use SSI criteria in determining Medicaid eligibility, but require a separate application.

Mental disorders include "schizophrenia," and "other psychiatric" disorders. Visit <www.ssa.gov/policy/programs/SSI> and see Table V in the document *Children Receiving SSI*, December 1999

As of December, 1999 almost 850,000 children (under age 18) were receiving SSI cash benefits; the majority of them are covered by Medicaid. Almost two out of three (64 percent) of the SSI children are disabled based on a mental disorder and the largest percentage (37 percent) have mental retardation.

For more information on the PRWORA, visit

<www.welfare-policy.org/prwora.htm>

The children's SSI program was changed significantly by the **Personal Responsibility and Work Opportunity Reconciliation Act** of 1996 (PRWORA). It restricted the SSI definition of childhood disability by stating: financially-eligible children must have a medically determinable physical or mental impairment that results in severe or marked functional limitations which can be expected to result in death or which has lasted or can be expected to last at least 12 months.

For more information about Section 4913 of the BBA that protects Medicaid for children losing SSI eligibility after their redeterminations under the new definition of disability visit

<www.hcfa.gov/medicaid/bbakids.htm>

Congress also directed SSA to review certain children who were receiving benefits to determine if they qualified under the new definition. Following the review of just more than 245,000 previously-eligible children, it is estimated that approximately 100,000 children will lose SSI benefits after completing all their appeals. To protect these children from losing their health coverage, Congress required States to continue Medicaid benefits for them under the Balanced Budget Act (BBA) of 1997. Despite this legal protection, however, there is evidence that some young people who lost SSI-benefits have also been inappropriately dropped from the Medicaid Program.

The law also requires SSA to redetermine the eligibility of individuals who are eligible for SSI at the time they turn age 18 using the adult eligibility criteria. As a result, some individuals who received benefits as children may no longer qualify under adult eligibility rules. Initial data from SSA about the first two years of the age 18 redetermination procedure indicates that approximately one-third of these young people have lost benefits.

Total number of individuals reviewed at age 18	**89,779**
Number of 18 year-olds whose benefits continue	**51,644**
Number of 18 year-olds who lost benefits after all appeals	**30,543**
Number of cases still pending resolution through appeals process	**7,592**

For the Annual Report of the Supplemental Security Income Program, SSA (May 1999) visit

<www.ssa.gov/OACT/SSIR/SSI99/index.htm>

For this age group, among the cases that had a final decision, the cessation rate was 39.4 percent in 1997 and 34.4 percent in 1998.

If individuals lose their SSI benefits due to a change in income or disability status, they may also lose their Medicaid benefits. Federal law, however, requires State Medicaid agencies to determine if individuals qualify for Medicaid through any other eligibility category before terminating coverage. Ongoing eligibility will depend on each State's categories of eligibility for adults with disabilities. Before their 18th birthday, these young people should begin investigating other categories that might provide continued coverage. Individuals who cannot qualify for Medicaid through another category are entitled to notice from the State agency and can appeal the decision to terminate coverage.

Home- and Community-Based Waivers. Under Federal law, States can request permission for the flexibility to serve certain groups of individuals without following certain normal legal requirements by filing a waiver. Through a waiver program, States have the option to provide Medicaid to specific populations of adults or children or to provide certain types of services. States can operate more than one waiver program at a time.

Many States operate a "home- and community-based services (HCBS) waivers" program that allows children with special health care needs to qualify for Medicaid based on their disability without considering their family income. These waivers allow States to provide Medicaid to qualifying children with disabilities who live at home, but who would be eligible for Medicaid if they lived in a hospital or nursing facility. The obvious advantage is that children can live at home and use Medicaid to access the home- and community-based services they need.

For more information about HCBS, visit

<www.hcfa.gov/medicaid/hpg4.htm>

Under a waiver program, States have the flexibility to select the waiver services that best meet the needs of the population they wish to serve and these services may be provided Statewide or limited to specific geographical areas. Therefore, States are allowed to target the HCBS waiver to individuals with a specific illness or condition, such as technology-dependent children.

Some states, such as Indiana, have a HCBS waiver that serves both children and families.

There are currently more than 200 HCBS waiver programs across the country and many States have more than one program. As of late 1999, 30 States have HCBS waivers for children with special health care needs. After young people "age out" of a children's waiver program, they may qualify for another HCBS waiver in their State that will provide continued Medicaid coverage.

Income-Based Eligibility for Older Children and Youth. Under Federal law, certain mandatory groups of children receive Medicaid on the basis of their limited income. Children below age 6 living in families with incomes up to 133 percent of the Federal poverty level (FPL) and children ages 6-14 living in families with incomes at or below 100 percent FPL are currently covered. The law requires that all children under age 19 who live below the FPL receive Medicaid by 2002. Under this provision, coverage is phased in one year at a time. However, States can expand the number of children who qualify for Medicaid through these mandatory poverty-level categories by accelerating the phase-in or raising the income eligibility level beyond the minimum. At this time, the majority of States and the District of Columbia have expanded coverage for children, particularly older children and adolescents.

For a detailed description of the EPSDT program, visit

<www.hcfa.gov/medicaid/epsdthm.htm>

As more adolescents qualify for Medicaid, they will benefit from EPSDT's comprehensive benefits. However, individuals who remain Medicaid-eligible after age 21 will only receive services included in the State plan. In most states, the services covered under the Medicaid state plan are not nearly as extensive as those provided to individuals under age 21 through EPSDT.

Eligibility for Working Adults with Disabilities

For various SSA work incentives, see

<www.ssa.gov/pubs/redbook99.htm>

SSI Work Incentives. Individuals receiving SSI benefits can take advantage of different work incentive programs that allow them to work and still qualify for public health insurance.

Federal Register April 15, 1999 (Volume 64, Number 72, Pages 18566-18571) and April 28, 1999 (Volume 64, Number 81, page 22903) Revision of 20 CFR 404.1574 and 416.974.

To receive SSI, individuals must either be unemployed or, if working, earn below what is called the "substantial gainful activity" (SGA) level. The SGA level was increased from $500 a month to $700 a month effective July 1, 1999. This increase—the first in almost a decade—is significant because it will allow individuals with disabilities to earn more each month and still qualify for cash benefits in some situations and for Medicaid in other situations.

Under Section 1619(a) of the Social Security Act, workers with disabilities can continue to receive SSI cash benefits even if they earn above SGA as long as they meet all other SSI eligibility requirements. This enables them to begin working and still receive cash benefits up to a certain income limit. As earnings increase, the SSI payment decreases and stops completely once income reaches an individualized "break even" point when, based on the Social Security Act's formula, they no longer receive any cash benefit. Through this Section 1619(a) provision of the Social Security Act, individuals receive both cash benefits and Medicaid.

Section 1619(b) of the Social Security Act allows individuals to receive Medicaid after their earnings exceed the SSI limits. Medicaid coverage continues until earnings reach a threshold that takes into account what is needed to cover health care costs and living expenses in an individual's home State. Each state's earnings threshold is based on the Federal benefit rate for SSI; the State's supplement to SSI, if any; and the State's average Medicaid amount for the year. These earning limits vary widely from state to state. (In 1998, the state-specific earnings threshold ranged from a high of $34,125 annually [$2,844 monthly] to a low of $13,792 annually [$1,149 monthly].) Individuals who can document that their medical needs are higher than average can establish an "individualized threshold" based on their own health care expenses. Through this provision, workers with disabilities can qualify for continued Medicaid if they have a disabling impairment, continue to meet all other SSI eligibility requirements except for their earnings, need Medicaid coverage to work, and lack sufficient income to replace Medicaid with private insurance.

To find out more about the earnings threshold, visit

<www.ssa.gov/pubs/redbook99.htm#1619B>

The SSI work incentives are complex, and few people use them. Recent SSA data indicate that among SSI disabled workers, only 9 percent were under age 22 (26,711 individuals) and another 24 percent were between ages 22-29 (82,186 individuals). Individuals who take advantage of SSI work incentives participate in the Section 1619(b) program in order to obtain access to Medicaid.

For the *Quarterly Report on SSI Disabled Workers and Work Incentive Provisions*, Social Security Administration, Office of Research, Evaluation and Statistics (June 1999) visit

<www.ssa.gov/statistics/ores_home.html>

Optional "Buy-In" for Working Adults with Disabilities. Historically, Medicaid was available only to individuals and families with the lowest incomes. Recently, Federal guidelines changed to allow more working adults with disabilities to qualify under certain conditions.

Under Section 4733 of the BBA of 1997, States can create a new optional "categorically needy" eligibility group. This new category allows States to provide Medicaid coverage to workers with disabilities who, because of their earnings, cannot qualify for Medicaid under other statutory provisions. In order to qualify, a worker with disabilities must have a net income less than 250 percent of the annual FPL and must otherwise qualify for SSI, except for their earnings. Under this option, eligible individuals can "buy into" Medicaid by paying monthly premiums to cover their health and long-term support services. States electing this option can establish a sliding premium rate based on income.

States also can define "family" for the purposes of this provision and can choose to consider young adults with disabilities who live with their parents as a "family of one" when calculating net family income. Qualifying workers with disabilities are exempt from the SGA rules, but they must meet the SSI rules for resource (less than $2,000 for an individual). In 2000, the income level below 250 percent of poverty for a family of one is $1,740 a month. However, Section 4733 allows States to measure the family's net income against the 250 percent family income standard. As the net income is determined by applying all SSI income "disregards" to the total income, this greatly increases the amount of income workers with disabilities can have and still qualify.

For more information about Section 4733 of the BBA, see November 24, 1997 and March 9, 1998 Letters to State Medicaid Directors at

<www.hcfa.gov/medicaid/bba>

Section 4733 does not require that eligible individuals have previously received SSI benefits to "buy into" Medicaid. Individuals who have not received SSI must obtain a disability determination from the Health Care Financing Administration (HCFA) to ensure that they qualify.

The chart below illustrates how young people with disabilities can work and still qualify for health care coverage through Medicaid.

LEGAL AUTHORITY	BENEFITS	ELIGIBILITY
Supplemental Security Income (Title XVI of Social Security Act)	Cash benefits and Medicaid for individuals who meet both financial and disability criteria	Qualifying SSI recipients who earn less than $700/month. The SGA limit of $700 applies to individuals who are not blind; if blind, $1,170. SGA applies only at initial determination; otherwise 1619(a) allows continuation despite SGA.
Section 1619(a) of Social Security Act	Decreasing cash benefit as income increases & Medicaid for individuals who meet disability criteria without a requirement to "spend down" resources	Qualifying SSI recipients who earn more than $700/month up to a certain income limit established by each State
Section 1619(b) of Social Security Act	Medicaid coverage for individuals who need it to work and who meet eligibility criteria	Qualifying SSI recipients until their earnings reach a threshold calculated to reflect the value of SSI, Medicaid, and the value of any publicly-financed personal care assistance
Section 4733 of the Balanced Budget Act of 1997	State option to offer Medicaid "buy-in" for working individuals with disabilities whose income exceeds 1619(b) limits	Qualifying SSI recipients as their earnings increase up to 250 percent FPL, based on their net income
Section 201 of Ticket to Work and Work Incentives Improvement Act	Medicaid coverage	Working individuals who reside in participating states, who are at least age 16 but less than 65, who meet state-specific income and resource limits and who lose SSI due to medical improvement but still have a medically determinable severe impairment.

For more information on the SGA, visit

<www.ssa.gov/pubs/redbook99.htm#SGA>

For more information on Section 1619(a), visit

<www.ssa.gov/pubs/redbook99.htm#1619A>

For more information on Section 1619(b), visit

<www.ssa.gov/pubs/redbook99.htm#1619B>

For more information on Section 4733 of the BBA, visit

<www.hcfa.gov/medicaid/twwiia/eligible.htm>

For more information on Section 201 of the TWWIIA, visit

<www.hcfa.gov/medicaid/twwiia/faq.htm>

Medically Needy Children and Adults

States can provide Medicaid to individuals who are defined as "medically needy." This option allows States to cover people who have too much income to qualify under the other mandatory or optional "needy" eligibility categories. Under the "medically needy" program, individuals are allowed to "spend down" to the state's Medicaid income limit by paying or incurring medical expenses to offset their excess income. States may also allow families to establish eligibility by paying monthly premiums that are equal to the difference between family income (reduced by unpaid medical expenses in previous months) and the state's Medicaid income eligibility standard.

For *Medicaid Eligibility for Individuals with Disabilities* by Andy Schneider, Victoria Strohmeyer and Risa Ellberger (July 1999) visit

<www.kff.org/content/1999/2150/>

Eligibility for the medically needy program does not have to be as inclusive as the categorically needy program. If States select this option, they must cover certain children under age 18 and pregnant women, but can decide what other groups to include. There are 40 medically needy programs that provide some services to certain individuals. To determine which specific groups of individuals are covered in a State, check with the State Medicaid agency.

Medicare

Overview

Medicare offers public health insurance for older individuals and certain people with disabilities. The program has two parts: hospital insurance (Part A) and supplementary medical insurance (Part B). Coverage for Part A is automatic for people who are 65 years old and older and for some people with disabilities; certain uninsured individuals can pay monthly premiums to obtain Part A coverage. Monthly premiums are required for Part B coverage. Qualified individuals can enroll by completing an application form at their local SSA office.

People under age 65 who are receiving Social Security (not SSI) benefits based on disability are entitled to Medicare after 24 months.

People with disabilities may qualify for both Medicaid and Medicare. According to the Kaiser Commission on Medicaid and the Uninsured, about one-fourth of Medicaid enrollees who have disabilities are also eligible for Medicare. These individuals can use Medicaid to supplement their Medicare coverage, and pay for deductibles, copayments, and other expenses that Medicare will not cover (for example, prescription drugs). For the group of individuals who can receive both Medicaid and Medicare ("dual eligibles"), Medicare will cover medical bills up to its limit and then Medicaid will cover the balance. Lower-income young people with disabilities may qualify for both Medicaid through their eligibility for SSI and Medicare through the Social Security Disability Insurance (SSDI) program.

Contact the local SSA office for Medicare information and the State Medicaid agency to learn more about dual eligibility in a specific State. For more information on how to contact a local SSA office, visit

<https://s3abaca.ssa.gov/pro/fol/fol-home.html>

Eligibility through Social Security Disability Insurance (SSDI)

The Old Age, Survivors and Disability Insurance (OASDI) Program (in Title II of the SSA and often called "Social Security") provides monthly cash benefits to workers who are retired or disabled and their dependents and survivors. OASDI for individuals with disabilities is generally referred to as "SSDI" to distinguish it from the SSI program.

The primary funding source for OASDI is the payroll tax (FICA) paid by workers who are covered by the program and their employers. Once individuals work long enough in covered jobs to be "insured," they and their families are eligible for benefits. The level of benefits received is based on the amount the worker earned in covered jobs. Because these benefits are considered part of an insurance program, they are paid regardless of financial need.

Most people view SSA or OASDI benefits as a program for older workers who are retired or disabled as well as their dependents or survivors. Children, however, may receive benefits if they are under age 18 and their parents worked enough to be insured and have retired, are disabled, or have died. Young people over age 18 can receive benefits if they have a disabling impairment that began before age 22 (commonly referred to as a "disabled adult child" [DAC]). However, young people may also earn SSDI benefits through their own work history. Once a young worker meets the minimum requirement (with as little as one and one-half years of work) SSA uses a formula that is adjusted for age to calculate what benefits are paid based on the amount of time worked.

The population of young workers with disabilities who may earn SSDI benefits is often overlooked. Because their FICA taxes can earn access to important health care coverage it is important to ensure that the work history of all individuals with disabilities is properly recorded by their employers, even if the job is in a sheltered or supported work setting. After beneficiaries receive SSDI for two years, they are eligible for Medicare.

SSDI Work Incentives

To encourage SSDI beneficiaries to work, SSA work incentive programs provide continued eligibility for Medicare.

Federal law provides a 45-month period for SSDI beneficiaries to test their ability to work while protecting their cash benefits and Medicare coverage. The period has two separate parts. The first is a nine-month "trial work period" (TWP) during which they can work and continue to receive all benefits, regardless of how much they earn. The work experience does not have to occur within a consecutive period of nine months. Months of work experience are generally considered during a rolling 60-month period.

A TWP month is one in which the SSDI beneficiary earns more than $200 or works more than 40 self-employed hours. See the SSA Redbook's Section on SSDI Work Incentives at <www.ssa.gov/pubs/redbook99.htm#TWP>

The trial work period is followed by a second 36-month "Extended Period of Eligibility" (EPE). During the EPE, SSDI benefits are suspended for any month that the individual earns above the SGA level of $700 adjusted gross income, but Medicare coverage continues for that time period. Premium-free Part A continues at least 39 months after TWP. Effective 10/1/00, Medicare continues at least 93 months after the TWP. However, the person still receives SSDI payments for that month and two following months, for a total of 12 months of SSDI payments during work activity. If the person is still disabled when the Medicare entitlement EPE ends, the individual can purchase coverage through monthly premiums (in 1999, $309 a month). Months of work experience are generally considered during a rolling 60-month period. Individuals who are under age 65, disabled and no longer entitled to free Medicare Hospital Insurance Part A because they successfully returned to work, may be eligible for the "Qualified Disabled and Working Individuals" (QDWI) program. This program helps pay Medicare Part A monthly premiums.

For more information on QDWI, visit

<www.ssa.gov/work/ResourcesToolkit/Health/qdwi.html>

State Children's Health Insurance Program (SCHIP)

Another publicly-funded health insurance option for youth through age 18 with chronic health conditions and disabilities is the new State Children's Health Insurance Program [SCHIP] (enacted in the BBA of 1997 as Title XXI of the SSA).

For *Children with Disabilities Under the State Children's Health Insurance Program* by Paul W. Newacheck (December 1997), Maternal and Child Health Policy Research Center visit

<www.mchpolicy.org/chip.html>

SCHIP has the potential to provide health care for millions of lower-income uninsured children and youth, including those with special health care needs. It is likely that children with complex and costly health conditions already have either public or private health insurance and will not seek assistance from the SCHIP. However, SCHIP offers tremendous hope for a larger population of uninsured children who have less severe or costly special health care needs (estimated to be one of every six children in the SCHIP target population of uninsured families whose income is below 200 percent of the FPL).

For *New Estimates of Children with Special Health Care Needs and Implications for the State Children's Health Insurance Program* by Paul W. Newacheck, et al. (March 1998), Maternal and Child Health Policy Research Center visit

<www.mchpolicy.org/chip.html>

SCHIP will provide about $4 billion a year for ten years in allotments to assist State efforts to initiate and expand child health assistance to uninsured, low-income children. Congress designed SCHIP to serve a target population of children whose family income is too high for Medicaid but is lower than 200 percent of the FPL, approximately $32,000 for a family of four. States can set different income eligibility levels.

The HCFA web site provides up-to-date information about the national SCHIP initiative and has links to SCHIP internet sites for information about specific State plans. Visit

<www.hcfa.gov/init/children.htm>

In order to receive SCHIP funds, a state must submit its State plan for review and approval by the Health Care Financing Administration (HCFA). Within broad guidelines, States can set their own eligibility criteria, benefits package and cost sharing requirements. A State can use SCHIP funds to expand Medicaid coverage, develop a separate State program, or combine the two approaches. HCFA reports that, as of February 2000, 24 States are using Title XXI to expand Medicaid, 15 have a separate child health program, and 17 are using a combination approach. A state can make minor amend-

Maternal & Child Health Policy Research Center publications about the SCHIP program and children with special health care needs, particularly *An Analysis of States' SCHIP Policies Affecting Children with Special Health Care Needs* by Harriette B. Fox, Regina R. Graham, Margaret A. McManus and Christine Y. Chen (April 1999) are available at

<www.mchpolicy.org/schip.html>

ments (changes) to its SCHIP without prior federal review. However Title XXI places limitations on the amount of time that an amendment can remain in effect prior to submission of the amendment to HCFA. A state that implements an unapproved State plan amendment risks the possibility that the plan amendment will not be approved as implemented. To date, HCFA has approved a total of 48 amendments, as submitted by 31 states; and amendments from 12 states are currently under review. As benefits, eligibility, and cost-sharing varies significantly from State to State, and from time-to-time in a given State, it is essential to know the status of a SCHIP plan and any new or proposed amendments when determining which children may qualify for this new and evolving program.

Key Questions

Eligibility for Medicaid

- Does the State provide automatic Medicaid eligibility for children who qualify for the SSI program?
- If SSI-eligible children do not automatically receive Medicaid coverage, what should families do to apply for Medicaid?
- Is the State continuing Medicaid for children who lost their SSI eligibility after a disability redetermination?
- Is the State notifying young people who lose their SSI eligibility at age 18 that they may continue to qualify for Medicaid through another eligibility category?
- What categories of Medicaid eligibility does the State provide for young adults with disabilities or chronic health conditions when they are no longer eligible for the EPSDT program after age 21?
- What criteria does the State use for its Medicaid home- and community-based waiver program for children with disabilities?
- What other Medicaid waivers are available to young adults with disabilities after they "age out" of the children's waiver?
- Does the State provide Medicaid to adolescents living in low-income families? What ages are covered? What are the income eligibility levels?
- Does the State have a "medically needy" program? Are young people with disabilities eligible for it?

Eligibility for Workers with Disabilities

- Can the individual qualify for Social Security's 1619 work incentive program?
- Does the State have a Medicaid "buy in" program for working adults with disabilities? If not, is the State planning to select this option soon?
- Does the individual meet all the eligibility criteria for the Medicaid buy-in (i.e., have annual net income less than 250 percent FPL; meet SSI disability criteria; meet SSI resource requirements)?
- Are young people with disabilities working and paying FICA payroll taxes that may allow them to qualify for SSDI benefits through their own work history?
- Are younger SSDI beneficiaries able to use the work incentive provisions that allow a "trial work period" and then an "extended period of eligibility" so they can continue to receive Medicare?

Eligibility through SCHIP

- Does the State provide Medicaid or Medicaid-like benefits to adolescents through the new SCHIP?
- What assistance is available from the SCHIP agency to assist youth to access other health care coverage when they turn 19 and age out of SCHIP?
- Does the SCHIP provide benefits needed by most or many special needs children? What are the differences between SCHIP benefits and Medicaid?

Private Health Insurance: Establishing and Maintaining Coverage

According to the Kaiser Commission on Medicaid and the Uninsured, only 54 percent of the individuals from age 18-64 who have a chronic disability have private health insurance. The following discussion highlights some major issues to consider for young adults who may qualify to continue coverage through their parents' private plan or who qualify for health benefits through their own job. A list of key questions to ask when exploring public health insurance coverage options and possible eligibility appears at the end of the section.

For more information on the Kaiser Commission visit <www.kff.org>

Jack Meyer and Pamela Zeller, *Profiles of Disability: Medicaid and the Uninsured Populations* (July 1999).

Overview

State laws provide certain protections for older children with disabilities when family health insurance coverage would otherwise end for children who do not have disabilities. To be eligible for extended coverage, an adult child must have a physical or mental disability, be unmarried, and depend on the covered parent for support. Some private plans require that the adult child also live with the supporting parent(s). Sometimes extended coverage is available only for full-time students.

The age limits vary greatly among private plans, although they generally cover children until their 19th birthday. Some plans permit children to continue on family coverage after age 19 while they are full-time students, but there is no standard insurance industry-wide age limit. Coverage for adult children with disabilities may sometimes extend to age 23, 25, or even later.

The National Association of Insurance Commissioners provides direct links to all 50 State insurance departments. Visit <www.naic.org> and choose "State Regula-tors" for direct links and a list of names and addresses.

Given the wide variation, **it is recommended that to ensure continued coverage families contact their insurance company or plan sponsor at least several months before the child turns age 19 to tell them that they have a dependent adult child with a disability.** Without this notification to the insurance company, the dependent's coverage will automatically terminate at the age specified in the plan. The family's plan should specify the age limit as well as the notification procedures that parents must follow when they want to continue coverage for an adult dependent child. Given the wide variation among State laws and individual policies, it is critical to obtain State-specific advice.

Children who qualify through their parent's group coverage and then lose eligibility by reaching the age limit can apply for individual coverage under protections afforded by a new Federal law, the Health Insurance Portability and Accountability Act of 1996 (HIPAA).

Health Insurance Portability and Accountability Act of 1996 (HIPAA)

For the Department of Labor's Pension and Welfare Benefits Administration (PWBA) consumer guide *Questions and Answers: Recent Changes in Health Care Law* that explains recent changes in Federal law which affects health benefits, visit

<www.dol.gov/dol/pwba> or call 1-800-998-7542.

For the appropriate regional PWBA office to contact with specific questions about rights of an individual with employment-based coverage visit

<www.dol.gov/dol/pwba>

The Health Insurance Portability and Accountability Act (HIPAA) of 1996 (sometimes called "Kennedy-Kassebaum" after the two senators who sponsored it) helps increase access to private insurance for people with disabilities and chronic health conditions. Although the law's key provisions took effect in 1997 or 1998, people are still learning about its implications, especially for individuals with disabilities and chronic health conditions. For group plans in effect before July 1, 1997, the law originally took effect on the first anniversary after June 30, 1997.

The law, which will primarily help individuals who can obtain group insurance through employers or unions, applies to both traditional insurance plans and health plans operated by employers who self-insure. As plans operated by self-insured employers are not regulated by State insurance laws, it is particularly helpful to have Federal rules for them.

HIPAA was designed to provide new protections for people who have or need private health insurance. Specific provisions in HIPAA allow individuals to obtain coverage even when they have past or current chronic health conditions, help individuals maintain coverage when they change insurance policies or jobs, and make insurance more accessible for some individuals.

Whether HIPAA will help more young workers with disabilities obtain private health insurance remains to be seen. Given the low percentage of this population who are able to obtain competitive jobs with benefits, it is unlikely that many will benefit from the new protections for group health insurance. There are important new provisions regarding individual insurance policies, but these policies may remain beyond the financial reach of many young adults with disabilities.

For links to State departments to contact with questions about individuals who do not have health insurance through their employers visit the National Association of Insurance Commissioners at

<www.naic.org>

HIPAA has implications for young people with disabilities.

- States are required to provide people losing group coverage access to individual insurance regardless of their health status as long as they meet certain criteria. This protection can help adult children who qualify through their parent's group coverage but lose eligibility when they reach the age limit. They can apply for individual coverage as an "HIPAA eligible individual" under the method chosen by the State to provide guaranteed availability of coverage (whether through an open market approach or a high-risk pool). Eligible individuals include those who have had insurance for at least 18 months where the most recent coverage was under a group health plan or COBRA (Consolidated Omnibus Budget Reconciliation Act of 1986) coverage described in the next section. Applications must be made within 63 days of losing the group coverage. Applicants are entitled to buy individual insurance policies or comparable coverage from a State's high-risk pool without a preexisting condition exclusion period (described in the next bullet). Contact the State Insurance Department for information about insurance carriers who offer individual policies or about the State's alternative mechanism.

- Group health plans and insurers can only apply pre-existing exclusions to individuals who do not have sufficient creditable coverage (without a significant break) to offset a pre-existing condition exclusion. A significant break is a period of 63 or more days during all of which an individual has no creditable coverage. If a pre-existing exclusion applies to a timely entrant, the maximum exclusion period allowed is 12 months (365 days) following enrollment for conditions treated within six months prior to enrollment. The maximum pre-existing condition that can be applied to a late enrollee is 18 months. HMOs that do not use a pre-existing exclusion may impose an "affiliation" period of 60 days for timely entrants or 90 days for late entrants. A late entrant is a plan member or dependent who does not enroll during: 1) the first period in which s/he is eligible to enroll; or 2) a special enrollment period when there is a

The Institute for Health Care Research and Policy, Georgetown University Medical Center provides consumer guides on what States are doing to comply with HIPAA. For more information, visit

<www.georgetown.edu/research/ihcrp/hipaa>

Note: To retain protections under HIPAA, individuals must avoid a 63-day break in coverage. Parents who lose or change jobs should continue coverage for themselves and their dependents through their old job if health insurance is not immediately available from a new job.

It is possible to buy group coverage for themselves and their families through the Consolidated Omnibus Budget Reconciliation Act (COBRA) option. The continued coverage is important because it helps adult children with disabilities reduce the pre-existing condition exclusion period and qualify for individual coverage through HIPAA.

The COBRA provisions -- including changes made by HIPAA -- may require the payment of premiums for the maximum allowable continuation period.

change in family status or loss of group coverage under another plan. The application of any pre-existing condition exclusion is reduced by the number of days in which a pre-existing condition exclusion is satisfied under any one of the following: an insured or self-insured group health plan; health insurance coverage; Medicare; Medicaid and Title X; Indian Health Service program; state high risk pools; public health plans; and Peace Corps benefits. The pre-existing credit does not apply to persons who have more than a 63-day lapse in coverage (or, for insured group health plans, as allowed by state law). Benefit waiting periods do not count as a lapse in coverage. A pre-existing condition exclusion period is measured from a person's enrollment date in the plan. A person may use creditable coverage s/he has prior to the enrollment date to reduce the maximum pre-existing period.

- Workers with disabilities now have greater access to employer-based group health plans. The law requires group health plans to treat all covered members the same regardless of their health status, charge the same premiums for the same coverage, and subject everyone to the same waiting period, if there is one. Each State is implementing the individual market requirements of HIPAA differently so it is advisable to check for State-specific information. As States can impose stricter obligations on health insurance companies, contact the State Insurance Commissioner with specific questions.

Consolidated Omnibus Budget Reconciliation Act (COBRA)

The cost of the COBRA plan includes the employers share as well as the employee's share of the health plan.

The Consolidated Omnibus Budget Reconciliation Act of 1986 (COBRA) allows certain individuals and their dependent children the right to temporarily continue health coverage at group rates when the employee is laid off or resigns—and sometimes, even when fired from the job. Although the continued coverage will cost more than the normal group rate, it is still less expensive than individual health coverage and provides time to find other family health insurance if it is not available through a new job. The law generally covers group health plans for employers who have 20 or more employees (to include part-time employees) except for plans sponsored by the federal government.

Health plans are required by law to notify individuals who are entitled to choose to continue benefits for themselves and their families. There is a 60-day period in which to accept coverage or lose all rights to COBRA benefits. If eligible, individuals must be offered the same group coverage that was previously provided by the employer.

The chart below describes the three criteria required for individuals to qualify for COBRA benefits.

CRITERIA	REQUIREMENT
Plan coverage	Generally applies to group health plans employing 20 or more employees, including part-time employees
Beneficiary coverage	Generally individuals, spouses, and dependent children who are covered by group health plan on the day before a "qualifying event"
Qualifying events	Certain types of events that would cause the beneficiary, spouse, and dependent children to lose health coverage without COBRA

The "qualifying event" determines who remains eligible for coverage under COBRA and how long those individuals may receive continued coverage. The chart which follows shows the effect of different qualifying events on employees, spouses, and their dependent children. A plan may provide periods of coverage longer than that required by COBRA.

HIPAA made two changes in the length of the COBRA continuation coverage period. First, the extended 11 months of coverage is available to both family members with disabilities and eligible family members who do not have disabilities. Second, the family members must notify the plan administrator within 60 days of a disability determination by the SSA and prior to the expiration of the 18-month period of COBRA coverage. (The old provision required that individuals be found disabled at the time of the "qualifying event" to receive extended coverage.)

QUALIFYING EVENTS	BENEFICIARY	LENGTH OF COVERAGE
Employee's loss of job except for "gross misconduct" ***OR*** reduced hours of employment (if this affects insurance eligibility)	Employee Spouse Dependent child	18 months; for persons with disabilities coverage may be extended by 11 months to a total of 29 months* *During the extended 11 months of coverage, premiums may be increased up to 150 percent of the plan's total cost of coverage.
"Dependent child" loses status (generally when child becomes an adult)	Dependent child	36 months
Employee eligibility for Medicare ***OR*** divorce/legal separation ***OR*** death	Spouse Dependent child	36 months

Extended COBRA benefits for individuals with disabilities are not widely publicized and many local SSA field offices are unfamiliar with these provisions. Individuals applying for COBRA disability determinations do not have to meet the nondisability requirements for SSDI (Title II) or SSI (Title XVI) to qualify for the extended coverage. It may be useful for local SSA field offices to contact their regional office for advice about how to process these requests. Individuals eligible for the extended COBRA coverage must notify the plan administrator within 30 days of a final determination from SSA that they are no longer disabled.

Key Questions

Eligibility for Extended Coverage through a Family Health Insurance Plan

- Can families include young adult children with disabilities after age 18 in family plans? What is the age limit for this extended coverage?
- Is the extended coverage available only to young adult children with disabilities who maintain status as a student?
- Is the extended coverage available only if young adult children with disabilities live at home?
- What documentation is required to show that adult children with disabilities are dependent upon their families?
- What medical documentation is required regarding their disability or chronic health condition?
- What should families do to ensure continued private health care coverage for their adult children with disabilities?

Eligibility for Individual Coverage

- What insurance companies in the State offer individual policies to young adults with disabilities who do not have access to group coverage through their families' plan or their own employment?
- What insurance companies participate in the State's open enrollment period for uninsured individuals? Which ones offer coverage for young adults with disabilities? When is the State's open enrollment period?
- Can uninsured young adults with disabilities access private insurance through an insurance pool established under the HIPAA?

- Can families afford the insurance premiums to continue coverage through COBRA for adult children with disabilities?

- Have families requested the necessary disability determination from the SSA to obtain the additional 11 months of coverage available through COBRA to qualifying persons with disabilities?

Health Care Implications of Federal Initiatives for Young People with Disabilities

Ticket to Work and Work Incentives Improvement Act (TWWIIA) of 1999

The Ticket to Work and Work Incentives Improvement Act of 1999 (P.L. 106-170) was passed in November 1999 with overwhelming support from Congress. This landmark legislation was designed to address some of the major barriers to employment faced by more than 7.5 million individuals with disabilities who receive SSI or SSDI benefits. The new law will provide:

For both the text of the law and the Conference Committee discussions where the final language was decided visit

<http://thomas.loc.gov> Report 106-478.

- Health care and employment preparation and placement services to individuals with disabilities to reduce their dependency on cash benefits;

- Incentives to States to allow workers with disabilities to purchase Medicaid to maintain employment;

- The option to workers with disabilities to maintain Medicare coverage;

- "Tickets to work" to individuals with disabilities so they can access services needed to obtain and retain employment and reduce dependence on cash benefits.

For a summary of the law and links to a SSA summary, visit <www.dol.gov> Department of Labor, Presidential Task Force on Employment of Adults with Disabilities.

Also see <www.ncd.gov> for a summary of the TWWIIA from the National Council on Disabilities.

Health Care Provisions

Expanding State Options under Medicaid. TWWIIA allows States to establish two new optional Medicaid eligibility categories for workers with disabilities:

- States can choose to cover individuals ages 16-64 with disabilities who, except for their earnings, would qualify for SSI. States can establish their own standards for assets, resources, and income.

- If States choose to cover the group described above, they may also cover workers who were eligible under the above group, but who lost that eligibility because their medical conditions improved, but who continue to have a "severe medically determinable impairment" as defined by Department of Health and Human Services (DHHS). States can establish their own asset, resource, and income standards under this group.

Individuals covered under these two options can "buy in" to Medicaid by paying monthly premiums or other cost-sharing charges on a sliding fee scale based on income. The State must establish the same premium or cost-sharing charges for both new eligibility groups. States may require individuals with incomes above 250 percent of the FPL to pay the full premium cost, but premiums may not exceed 7.5 percent of income for those with incomes that are 250 - 450 percent of the FPL. States must require individuals with incomes above $75,000 a year to pay the full premium. Although States may choose to subsidize costs for these individuals, they may not use Federal matching funds to do so.

In States that offer the Medicaid "buy in" programs, young workers with disabilities could pay monthly premiums to obtain coverage for medical expenses and long-term support services they cannot access through an employer or purchase from a private insurer. It may also be possible for young workers with disabilities to continue Medicaid when their impairment no longer meets Federal disability guidelines. The effective date for these provisions is October 1, 2000.

Testing Demonstration for Workers with Potentially Severe Disabilities

Under the new law, the Secretary of DHHS can approve State demonstration programs that will provide medical assistance equal to that provided under Medicaid to "workers with potentially severe disabilities." The demonstration authority covers individuals ages 16-64 who meet a State definition of physical or mental impairment, are employed, and are reasonably expected to eventually meet the SSI definition of disability if they do not receive Medicaid. State definitions of "workers with potentially severe disabilities" can include individuals who have congenital conditions as well as individuals who have conditions or injuries acquired through illness or accident as children or adults.

The provision is designed to provide a Medicaid buy-in for workers with disabilities whose conditions are not yet severe enough to qualify for SSI. Under this provision, young workers with disabilities can help test if providing early access to insurance can delay or prevent the onset of a fully disabling condition and if providing Medicaid can help them remain in the workforce and avoid the need to apply for public benefits.

The law authorizes the demonstration at $250 million over 6 years. These provisions are effective October 1, 2000.

Extending Medicare Coverage for SSDI Recipients

SSA policy allows SSDI beneficiaries to test their ability to work during a 9-month "trial work period" without affecting their disability or Medicare benefits. After this trial period, disability payments stop when a beneficiary's monthly earnings equal or exceed the SGA level ($700/month). The TWWIIA allows SSDI beneficiaries who are working to receive an additional 54 months of Medicare coverage. When this coverage period expires, individuals who are still disabled may continue Medicare by paying the premium.

For more information on TWWIIA, visit

<www.ssa.gov/work/ResourcesToolkit/legisregfact.html>

This provision will encourage young people with disabilities who qualify for SSDI benefits to explore employment options knowing that they can receive Medicare coverage for a longer period before having to pay monthly premiums. The effective date for this provision is October 1, 2000.

Presidential Task Force on Employment of Adults with Disabilities

The Presidential Task Force on Employment of Adults with Disabilities (PTFEAD) was created to develop a national policy to bring adults with disabilities into gainful employment at a rate that is as close as possible to that of the general adult population. Among its responsibilities, the Task Force was directed to develop and recommend options to address health insurance options and analyze youth programs related to employment.

For information about the Presidential Task Force on Employment of Adults with Disabilities visit

<www.dol.gov/dol/_sec/public/programs/ptfead/main.htm>

The Task Force has a number of Interagency Committees, including a Subcommittee on Expanding Employment Opportunities for Young People with Disabilities that is co-chaired by representatives from the Department of Health and Human Services/ Administration on Developmental Disabilities (ADD) and the Department of Education/ Office of Special Education and Rehabilitative Services (OSERS). Member agencies and offices of the Youth Subcommittee include:

- Department of Education: Rehabilitation Services Administration, Office of Special Education Programs, Office of Vocational and Adult Education, Office of Postsecondary Education, Office of Bilingual Education and Minority Language Affairs;
- Department of Health and Human Services: Maternal and Child Health Bureau Division of Services for Children with Special Health Needs, Substance Abuse and Mental Health Services Administration, Office of Civil Rights, Office of Family Assistance, Office of Community Services;
- National Council on Disability;

1999 Report to the President: *Re-charting the Course: If Not Now, When?* This report submitted November 15, 1999, is the second in a series of reports to be submitted to the President in accordance with Sec. 1(d)(2) of the Executive Order. It is located on the web at

<www.dol.gov/dol/_sec/public/programs/ptfead/ifnotnow.htm>

The Task Force will submit a final report on July 26, 2002, the 10th anniversary of the initial implementation of the employment provisions of the Americans with Disabilities Act of 1990. The reports will describe the actions taken by, and progress of, each member of the Task Force in carrying out the Executive Order.

Also, see *Re-charting the Course: If Not Now, When? Reports of the Committees of the Presidential Task Force on the Employment of Adults with Disabilities*. This document will compile reports from the seven Committees and Subcommittees of the PTFEAD into one comprehensive volume and is available via the web at

<www.dol.gov/dol/_sec/public/programs/ptfead/activities.htm>

- Department of Labor: Women's Bureau, National Youth Programs Office, Employment and Training Administration Disability Initiatives Unit, President's Committee on Employment of People with Disabilities;
- Department of Labor: National School to Work Office (jointly administered with Department of Education);
- Department of Justice: Office of Juvenile Justice and Delinquency Prevention;
- Social Security Administration: Office of Disability and Income Support Programs, Office of Employment Support Programs, Office of Policy, and Office of Policy.

Members of the Youth Subcommittee recognize the critical importance of health care and are exploring recommendations to help increase access to health insurance for young adults in transition from high school to the job market.

Note: Visit <www.gotowork.org> for recent interagency conferences on disability and employment sponsored by: SSA; DoE/NIDRR; DoL; and HRSA/MCHB. October 1998 *Youth and Employment* and July 1999 *Innovative Ways to Change Existing Policy Barriers on Employment for Youth 14-30 with Disabilities.*

SSA State Partnership Initiative (SPI)

For more information about the SPI visit

<www.ssa.gov/work/statepartnershipinitiative.htm>

The SSA's State Partnership Initiative [SPI] (established as a Task Force activity under Executive Order 13078) is designed to increase job opportunities through State partnerships supporting service delivery systems that consolidate current income, benefits, and supports for adults with disabilities into one coherent program.

SPI awarded cooperative grants to 12 States (California, Illinois, Iowa, Minnesota, New Hampshire, New Mexico, New York, North Carolina, Ohio, Oklahoma, Vermont, and Wisconsin) for demonstration projects to develop the infrastructure and partnerships for employment services to help adults with disabilities re-enter the workforce. All grantees must develop methods to ensure that participants continue to have affordable, adequate health- and long-term care after they begin working. Strategies may include requesting appropriate program waivers from HCFA or implementing Section 4733 of the BBA that allows States to offer a Medicaid "buy in" for workers with disabilities who have incomes above the current Medicaid criteria.

Projects will be evaluated based on a set of performance indicators including the State's ability to increase the number of beneficiaries who have health care coverage (including private insurance) after leaving the SSI program or who continue to have health care after receiving reduced SSI benefits.

Grantees have discretion to select their own demonstration sites, target populations, and number of participants. Illinois has specifically identified youth as part of its target population and has four pilot sites serving youth with cognitive disabilities in three high schools and one university. States actively pursuing Section 4733 of the BBA to support health care and long-term supports include Iowa, New Hampshire, and Wisconsin.

US Department of Health and Human Services (DHHS)
Health Resources and Services Administration (HRSA)
Maternal and Child Health Bureau's (MCHB) Healthy and Ready to Work (HRTW) Initiative

In 1996, through HRSA's Special Projects of Regional and National Significance (SPRANS) funding mechanism, MCHB implemented nine HRTW demonstration projects that address transition issues for young people with special health care needs. The States in which these projects reside are California, Iowa, Kentucky, Louisiana, Massachusetts, Maine, Minnesota, Ohio, and Oregon. The MCHB also funds the National HRTW Resource Center at the Institute for Child Health Policy to provide technical assistance to the projects and to State Title V programs. It also serves to promote interagency partnerships on the federal level.

For more information about the HRTW initiative, information about how to subscribe to the HRTW electronic mailing list, and for information about each of the demonstration projects, including a list of materials and products which are available visit

<www.mchbhrtw.org>

The HRTW initiative focuses on 1) youth with special health care needs (YSHCN) in transition to adulthood, 2) promoting wellness and improved access to appropriate health care for YSHCN, 3) moving YSHCN from the pediatric to adult health care system and 4) reducing health crisis episodes to enable YSHCN to optimize their transition from secondary to post-secondary education, employment, and self-sufficiency.

In September 1999, the MCHB-DSCSHN published "Measuring Success for Healthy People 2010." This publication contains six performance outcomes to be achieved and used in implementing the National Agenda for Children with Special Health Care Needs. The six performance outcomes are critical components of a community-based, integrated system of care.

The HRTW projects are reporting outcome information in categories corresponding to the six national MCHB performance measures. The measures assess the health and well-being of children with special health needs, including issues such as employment status, access to a medical home (not a place, but a system of services that is community-based, culturally competent, comprehensive and continuous), and a source of health insurance.

For more detailed information about this performance outcome, visit <www.mchbhrtw.org/HP2010.htm>, which contains the excerpt from the "National Agenda for Children with Special Health Care Needs: Measuring Success for Healthy People 2010." You may also access the MCHB-HRTW Fact Sheet at

<www.mchbhrtw.org/mchbfactsheet.htm

One of the six outcomes relates specifically to the transition of youth with special health care needs from pediatric to adult health care, post-secondary education and/or employment and independence. This outcome is to ensure that:

> "All youth with special health care needs receive the services they need to make necessary transitions to all aspects of adult life, including adult health care, work and independence."

HRTW, as a national initiative of the MCHB, is designed to help ensure that this performance outcome is met.

Department of Education Systems-Change Projects

For more information about OSERS visit

<www.ed.gov/offices/OSERS/RSA/PGMS/RT/appintro.html>

Through the Department of Education's Rehabilitation Services Administration (RSA), the Office of Special Education and Rehabilitative Services (OSERS) is supporting five systems-change grants to complement the SSA demonstration projects. This is a collaborative effort with the Department of Labor as part of the Systems-Change Interagency Workgroup, established by OSERS as part of Executive Order 13078.

The RSA grants focus on increasing competitive employment opportunities for individuals with disabilities who receive public support. "Competitive employment" is defined as work in the competitive labor market that is performed on a full-time or part-time basis in an integrated setting for which an individual is compensated at or above the minimum wage, but not less than the customary wage and level of benefits paid by the employer for the same or similar work performed by individuals who do not have disabilities.

Improving access to health insurance for individuals with disabilities who obtain jobs is one systemic barrier that the demonstration grants must address. Among the strategies they will explore to ensure continued access to long-term and health-related services is requesting the necessary waivers for States to offer a Medicaid buy-in for working individuals with disabilities.

The States receiving demonstration funding include Iowa, Colorado, Arkansas, Oregon, and Alaska. Each of the grants is for approximately $500,000 and they are the first of a five-year $12 million effort to facilitate system-change approaches. The awards were made to consortiums that include, at a minimum, the State agencies for vocational rehabilitation, welfare, education, and employment/employment training. In four States, the medical assistance agency is a collaborating partner. States have the flexibility to identify the specific groups they wish to target and three (Arkansas, Iowa, and Oregon) indicate that youth are a priority.

CONCLUSION

Young people with disabilities and chronic conditions leaving high school and making future educational and vocational plans must carefully consider available health insurance options. Although some jobs provide health coverage, there is no guarantee of coverage, especially for those able to work only part-time. Recent Federal legislation gives States several new options that can increase access to publicly-funded health insurance for workers with disabilities. The challenge is to educate young people with disabilities and their families about how to obtain adequate health care coverage that they need to enter and remain in the workforce.

APPENDIX OF ACRONYMS

ADD	Administration on Developmental Disabilities
BBA	Balanced Budget Act
COBRA	Consolidated Omnibus Budget Reconciliation Act of 1986
DAC	Disabled adult child
DSCSHN	Division of Children with Special Health Needs
DHHS	Department of Health and Human Services
EPE	Extended period of eligibility
EPSDT	Early and Periodic Screening, Diagnosis and Treatment
FPL	Federal poverty level
HCBS	Home- and community-based waivers
HCFA	Health Care Financing Administration
HIPAA	Health Insurance Portability and Accountability Act of 1996
HRSA	Health Resources and Services Administration
HRTW	Healthy and Ready to Work
MCHB	Maternal and Child Health Bureau
OASDI	Old Age, Survivors and Disability Insurance
OSERS	Office of Special Education and Rehabilitative Services
PCA	Personal Care Assistance
PRWORA	Personal Responsibility and Work Opportunity Reconciliation Act of 1996
PTFEAD	Presidential Task Force on Employment of Adults with Disabilities
PWBA	Pension and Welfare Benefits Administration
RSA	Rehabilitation Services Administration
SCHIP	State Children's Health Insurance Program
SGA	Substantial gainful activity
SPI	State Partnership Initiative
SSA	Social Security Administration
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income
TWP	Trial Work Period
TWWIIA	Ticket to Work and Work Incentives Improvement Act of 1999

Notes

Notes

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